Profiles of Nursing Home Residents on Medicaid

July 2006

THE HENRY J. KAISER FAMILY FOUNDATION

THE KAISER COMMISSION ON
Medicaid and the Uninsured

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Claudia Williams
AZA Consulting

James Rosen

and

Molly O'Malley
Kaiser Commission on Medicaid and the Uninsured

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OVERVIEW

According to a recent industry survey, the average cost of a private nursing home bed in the US was just over $6,000 a month in 2005.[1] This high cost makes nursing home services affordable for only the wealthiest Americans or those with private long-term care insurance. Medicaid, a federal and state funded health care program, covers nursing home care for low-income elderly or disabled individuals who meet income and asset standards. More than $100 billion was spent on nursing home services in the US in 2003, nearly half of it (46 percent) from Medicaid.[2]

In February 2006, Congress passed the Deficit Reduction Act (DRA) which made several key changes to Medicaid long-term care services. The DRA requires states to tighten eligibility for Medicaid nursing home coverage while at the same time made changes that were intended to make it easier for states to provide home and community-based services. Over the past ten years there has been a significant shift in the distribution of Medicaid long-term care resources from institutional to home-and community-based services, but the majority of Medicaid long-term care spending continues to be for institutional services. Further, there are limits on the availability of community services and significant variation in the extent that community services are available across the states.

This study aims to illustrate through case examples the experiences and challenges of low- and modest-income people who rely on Medicaid to pay for nursing home expenses. These case examples were developed through in-person interviews with nursing home residents and their families in three states. The first section of the report summarizes the themes and issues shared across the interviews we conducted, while the second section presents the individual stories of a subset of those we interviewed.

As we learned in this study, families want to keep loved ones at home, but lack the financial resources and necessary community supports to do so. Families with some resources can use substantial sums to pay for in-home care, drug costs, and assisted living and nursing home services. Even these large sums, however, do not cover long-term care services for extended periods, and families turn to Medicaid as a last resort when personal resources run out. As our population ages, demands for long-term care and concern about financing it will only increase. Medicaid will continue to play a critical role for families with low and modest incomes. Policies must balance concern with cost growth with real understanding of the needs of and challenges faced by these families with limited means.

[1] Based on MetLife 2005 survey of daily private-pay rates for private room in nursing homes.
[2] O'Brien, Ellen. "Medicaid's Coverage of Nursing Home Costs: Asset Shelter for the Wealthy or Essential Safety Net?" Georgetown University Long Term Care Financing Project, Issue Brief, May 2005.

STUDY DESIGN

We conducted interviews with the families of 15 nursing home residents in three very different locations: a large city in Georgia, a rural Kansas town, and a small city in Virginia. The residents were all recently enrolled in Medicaid. While several had some ability to pay for care before becoming eligible for Medicaid—and had gone through Medicaid spend-down—none had enough resources to cover a multi-year nursing home stay. We recruited the interviewees with the help of nursing home administrators at the three sites. Table 1 below describes the participants in this study. Pseudonyms were used to protect the privacy of families we interviewed.

During the interviews, we asked families about:

- How they handled the needs of their family member before the nursing home transition;
- The reasons the family member entered a nursing home;
- The income and assets families had and how they used these resources, including to pay for care;
- Their experience with the spend-down and eligibility and enrollment processes for Medicaid.

Table 1. Study Participants

Nursing Home Resident	Age	Location	Family Profile
Emily	92	Atlanta, Georgia	Emily's husband John lives nearby in an assisted living facility and visits everyday.
Mai	78	Atlanta, Georgia	Mai is visited each evening in the nursing home by her daughter Le.
Larry	63	Rural Kansas	Larry's wife Joan juggles working, a long commute and visiting him in the nursing home.
Pearl	84	Rural Kansas	Pearl's granddaughters Melanie and Jocelyn cared for her before she entered the nursing home.
Robert and Marian	87 and 85	Charlottesville, Virginia	Robert and his wife Marian share a nursing home room at a facility close to where their daughter Alice lives.
Roy	78	Charlottesville, Virginia	Roy never married; his niece Lucy helped him find a nursing home.
Natalie	78	Charlottesville, Virginia	Last year Natalie moved to a nursing home nearby her daughter Ellen.

MAJOR FINDINGS

While the individual circumstances and experiences of interviewees varied, the case studies revealed several common themes:

Families want to keep loved ones at home, but lack the resources and necessary supports to do so. On their own, families have limited ability to meet the increasing needs of older family members. Adult children cannot afford to leave the work force to care for aging parents and aging spouses often lack the strength and agility to help with daily needs such as getting out of bed and bathing. John, for instance, sought home care assistance when, because of his own failing health, he could no longer lift his wife Emily from bed to go to the bathroom. Ellen began to investigate nursing home options when her mother Natalie, who suffers from Alzheimer's, started wandering from home after part-time home care workers left for the day. Many of the families profiled cared for their ailing family members for years before becoming overwhelmed by care needs and the high cost of providing care in the community.

Unable to meet home care needs on their own, families with some resources hire aides to help. These families reported challenges identifying, supervising and retaining qualified home assistance. Once private funds dry up families often resort to nursing home care in order to obtain Medicaid services. Many families expressed frustrations that while Medicaid pays for nursing home services, they could not find or obtain the home-care services that permit family members to remain at home.

Families could not obtain adequate services in the community. Home and Community-Based Services (HCBS) are limited in the community. Community-based services are a growing component of Medicaid long-term care services, with significant resources allocated through the HCBS waiver program. Under this waiver program states can use Medicaid funds to pay for home care as an alternative to nursing home services. Despite the recent growth in these programs, none of the families we interviewed had relied on and most had never heard of HCBS programs. Some families, such as Natalie and Alice's in Virginia, were familiar with HCBS but found it did not cover the hours needed or provide the control desired for hiring aides. Ellen, for instance, was not able to take advantage of county home care assistance because of the requirement that a family member be home when the care giver arrived and departed. Her son Michael lived with her, but because of work demands could not be home during the day. In Roy's case the poor condition of the house, the high cost of the care and concern about leaving him alone for any period of time, made in-home care an unworkable option. Assisted living was also not an alternative because of Roy's inability to walk.

Families view Medicaid as a last resort after personal resources are depleted. Even seemingly large savings do not go far in paying for long-term care services. While some families we interviewed had very limited income and assets, others had nest eggs from retirement accounts, inheritance and house sales. Faced with medical expenses, drug bills, the cost of retrofitting homes to accommodate declining health and monthly bills for at-home care or assisted living, these sums are quickly depleted. It is a relief to families to know they can rely on Medicaid to pay for long-term care when their own resources run out.

The amounts families spend out-of-pocket can be staggering. Over the course of four years, Emily and John in Georgia spent over $165,000 on in-home care, nursing home services and prescription drug costs while Robert and Marian in Virginia spent about $40,000 on assisted living expenses. Even though these assets are exempt, Pearl sold her farm in Kansas and used these resources to pay for care.

Multiple transitions characterize the years leading up to nursing home admission. Many of the people profiled moved at least once in the period before entering a nursing home. These moves are especially disruptive for a family member with dementia or other health problems. Transitions were linked to two main issues: (1) The difficulty families face juggling home life and caretaking for elder relatives, as for Mai in Georgia who made moves from one child's house to another as the caretaking burden increased or changed; and (2) Challenges finding convenient and high quality facilities that offer a spectrum of care and accept Medicaid, such as those facing Larry and his family in Kansas. Moves were also made from one facility to another because of inability to get Medicaid coverage, limits in the care types offered and quality problems such as the development of chronic pressure sores. Even a hospital stay could translate into more moves and potential disruption depending on the availability of beds when returning to the nursing home facility.

Long-term care insurance is not a viable option for most. The monthly amount paid for long-term care insurance is expensive when purchased as a 70 year old but can be more affordable if bought earlier in life, well before care is needed. Because this coverage was not available when profilees were younger and because their modest wages as salesmen, farmers, factory workers, dieticians and homemakers might not have afforded them sufficient income to pay for it even at the cheaper prices, long-term care insurance is not a viable option for this group.

The experience of caring for loved ones has brought home the importance of this coverage to caretakers, however. Several of the family members we interviewed, such as Lucy and Alice in Virginia, have recently purchased long-term care coverage. Lucy pays $20 a month for a subsidized plan through her employer. With slightly higher incomes than their older relatives and a lower cost of coverage for younger applicants, private long-term care insurance is more affordable for these caretakers.

Obtaining Medicaid coverage can be confusing and complicated. While families with low incomes and no assets seemed to find the Medicaid eligibility process fairly straightforward, that was not the case for families going through a spend-down process, which required assembling dispersed records and documenting medical expenses. Even families with lots of experience and knowledge of the health care system were often confused and overwhelmed by the documentation required. Families expressed confusion over the rules about what money counted and did not count towards their Medicaid eligibility status. Families who could afford to do so such as Roy's in Virginia and Emily's in Georgia turned to elder care attorneys for help sorting through the process. But many cannot afford this assistance. Concerned social workers and nursing home admissions staff also provide much-needed support and help for families during the eligibility process.

CONCLUSIONS AND POLICY IMPLICATIONS

As we learned in this study, families with some resources can use substantial sums to pay for in-home care, drug costs, and assisted living and nursing home services. Even these large sums do not cover long-term care services for extended periods, however, and families turn to Medicaid when private resources run out.

Despite recent growth, Medicaid financed Home and Community-Based Services (HCBS) are still not sufficiently available in many communities. And when they are available, waiting lists may preclude individuals from accessing necessary services and services may not include enough hours to meet needs in the community. The lack of viable HCBS is a substantial barrier for families who would prefer to keep family members at home, but enroll them in nursing homes in order to obtain necessary services that are not available in the community. Families who turned to nursing home care could not keep their family member in the community without substantial support – they needed financial assistance and around-the-clock caretaking help.

In recognition of this need, the DRA allows states to expand HCBS as an optional Medicaid benefit to seniors and persons with disabilities up to 150% of the federal poverty level ($14,700 for an individual in 2006) without getting a federal waiver. These new rules gives states more leeway and flexibility in establishing programs and will hopefully lead to increased availability of HCBS in many communities. Despite this new flexibility, however, states are likely to continue to face challenges funding these program services. Reflecting these budget concerns, states will continue to have the option to establish enrollment caps and maintain waiting lists under the new rules.

States that take up the HCBS option must also rebalance their eligibility standards so that there are more stringent criteria for institutional services. While states could make it easier to receive community services, states could also make it harder for individuals to qualify for institutional services. Additionally, HCBS programs will continue to face challenges hiring, training, retaining and supervising qualified staff and maintaining quality of services.

The DRA requires states to tighten eligibility for Medicaid nursing home coverage. Medicaid's long-term care eligibility standards generally require an individual to have no more than $2,000 in countable assets, excluding a primary residence that is owned. Countable assets include savings accounts and investment. Under current law, individuals who transfer assets for less than fair market value in a specified period before applying for Medicaid (the so-called "look back" period) are penalized by the denial of nursing home coverage for a period reflecting the amount transferred. The new law requires states to extend the look back period from 3 to 5 years and changes the start of the penalty period from the date of the transfer to the date of Medicaid eligibility. In addition, the DRA excludes Medicaid coverage for individuals with home equity in excess of $500,000.[3]

This study does not address the prevalence of asset transfers[4] but other studies have generally found low asset levels and rates of asset transfer among nursing home residents.[5] Many families included in our study did use their own resources to pay for long-term care services, sometimes spending considerable amounts. Confused about Medicaid eligibility rules, families sometimes spend more of their own resources than is required under Medicaid rules or take actions that make them ineligible. Robert and Marian, for instance did not retain the $2,000

[3] States have the option to raise this amount to $750,000.

[4] Because of the small number of interviews, qualitative design and purposeful sampling of nursing home residents with modest incomes.

[5] O'Brien, 2005 and T. Waidmann and K. Liu, "Asset Transfer and Nursing Home Use: Empirical Evidence and Policy Significance," Urban Institute for the KCMU, April 2006.

in allowable assets when they became eligible for Medicaid. Pearl lost her Medicaid eligibility when she sold her house and farm. Unsold, the house was an excludable asset for Medicaid eligibility. Pearl used the proceeds from the sale of her house to pay for her care until she spent down to Medicaid eligibility levels.

Policy interest has also turned to encouraging private long-term care insurance as an alternative to Medicaid. The DRA will allow more states to develop Long Term Care Partnership programs. Under these programs, individuals who have exhausted privately purchased long-term care insurance can retain some of their personal assets and still become eligible for Medicaid. While a potentially good option for families who can afford it, these programs will be of limited utility to people such as those we profile in this report. None of the nursing home residents whose families we interviewed considered buying long-term care insurance because of its high cost and limited availability in the years when they might have purchased it.

Today, the challenges of paying for nursing home care are acute for many families and for the Medicaid program. As our population ages, demands for long-term care services and concern about financing it will only increase. Medicaid will continue to play a critical role for families with low and modest incomes. Policies must balance concern with cost growth with real understanding of the needs of and challenges faced by these families with limited means. The two goals need not always be in conflict. Increased availability of high quality HCBS, for instance, will respond to families' strong desires to keep family members at home, while potentially providing a more cost-effective alternative to nursing home services.

Individual Profiles of Nursing Home Residents on Medicaid

Family Profile: **Emily is 92. Her husband John lives nearby in an assisted living facility and visits everyday.**

Location: **Atlanta, Georgia**

Emily entered the nursing home in January 2003 at the age of 89. She has a multitude of health problems including Parkinson's disease, poor eyesight and incontinence and is confined to a wheel chair. Her dentures were stolen during a previous nursing home stay and her advanced Parkinson's makes it impossible to take a new imprint of her mouth. Without dentures, she can only eat soft food.

Emily has also suffered from depression for almost 50 years. Between bouts of depression and hospitalization she was able to work intermittently as a salesperson in a dress shop. Her husband John, who worked on contract as a salesperson for a homebuilder, has been in a caregiver role for many years. As his health declined he hired nursing aides to help at home, but found it difficult to find and retain qualified workers. After several attempts to provide around-the-clock nursing care at home, John decided he could no longer meet his wife's needs there—even with the support of full-time nurses. Emily entered the nursing home as a private-pay resident and within 5 months spent down to Medicaid eligibility. Her husband visits her everyday.

Before Emily qualified for Medicaid, she and John had assets in the form of CDs, stocks and IRAs. They had never owned a home. Round-the-clock home nursing for several years followed by the monthly $6,000 cost of nursing home care quickly depleted their assets. In the period from 1999 to 2003 the couple spent more than $165,000 on in-home care, nursing home care and prescription drugs (see chart at right). With only an amount left for John's continued expenses in the community, John turned to Medicaid for help in covering Emily's nursing home care. John navigated the Medicaid eligibility process with the help of an elder care lawyer and the assistance of the nursing home human services director. Emily enrolled in Medicaid in 2003.

John and Emily: Personal Spending on Home Care, Nursing Home Care and Medicine, 1999 – 2003	
In-Home Nursing Care	$92,030
Nursing Home Expenses	$61,081
Prescription Drugs	$12,298
Total	**$165,409**

Emily's husband's thoughts on qualifying for Medicaid and the expense of in-home care:

The lawyer told me when I get to a certain point I would be eligible, and as these expenses hit me…I got to that point…I had spent an awful lot of money with these women at home. That was my biggest expense. Had it 'round the clock. Had to. I could not help her to the bathroom.

Family Profile: **Mai is 78, and is visited each evening in the nursing home by her daughter Le.**

Location: **Atlanta, Georgia**

Mai entered the nursing home in December 2003, simultaneously qualifying for Medicaid. She is 78 years old, has dementia and diabetes, can no longer walk and has suffered several strokes over the past seven years. She is confined to bed and a wheel chair and complains of pain. Until recently, she was able to accompany her daughter Le on occasional family trips, but this is increasingly difficult. As Mai's dementia has progressed, she has lost the ability to speak English, reverting to her native Vietnamese, making communication with the nursing home staff very difficult. Le visits every day, checking her mother's chart, translating her mother's complaints and often bringing her lap dog to cheer Mai.

As Mai's health began to fail several years ago, she shuttled among her children as they took turns caring for her, a less than ideal situation for a woman with emerging dementia. Newly settled in Atlanta with Le, Mai participated in an adult day care program, which allowed her to interact with people and relieved the burden on Le. This came to an end, however, after Mai suffered a fall from her wheelchair transiting to the day program. Facing the prospect of caring for her house-bound mother with no access to affordable home care (Mai was on waiting lists for subsidized in-home care), Le decided it was time to consider full-time nursing care in a residential facility.

Le went with Mai to the face-to-face interview for Medicaid and made sure all her finances were documented. With very limited income—nothing but social security and virtually no assets—Mai easily qualified for Medicaid and moved to the nursing home. Mai's children are still disappointed their mother could not have stayed at home but are relieved she has a safe, permanent and comfortable place to live.

Le's reflections on the decision to have her mother enter a nursing home:
It was really difficult because my family has always thought it's better to take care of them in-home, but when she's staying by herself and she needs help just to go to the bathroom…it's better for her to be with other people….Unless the care is round-the-clock, trying to do in-home care and work is really difficult.

Her thoughts on choosing a nursing home*:*
It is a daunting task to look (at nursing homes). Even when I researched day programs I looked at six different (sites). I would check it out in the morning. I would take my mother. I would see what the residents were doing, what the activities were.

Family Profile: **Larry is 63. His wife Joan juggles working, a long commute and visiting him in the nursing home.**

Location: **Rural Kansas**

Larry, a formerly self-employed construction worker, father and grandfather, entered a nursing home in 2001 at age 58. After first showing signs of dementia in his 40s, Larry's health and mental capabilities slowly declined. Larry's wife Joan, along with her father and brother, looked after Larry, trying to keep him from driving after three traffic accidents.

As Larry's health deteriorated, the family's financial situation collapsed. Joan, who was not used to managing the family's finances, let Larry's long-term disability insurance policy lapse, depriving the family of a critical safety net. Without Larry's income Joan was not able to pay the family's bills. She filed for bankruptcy and took a job cleaning houses; her first job outside the home.

After many years living in a large city, Joan moved the family to a more rural area to be closer to two of the couple's adult children. Disrupted from the move, Larry's condition deteriorated and after a month-long hospital stay to evaluate his condition, Joan reluctantly placed him in a nursing home following a doctor's advice. She hunted for a suitable facility for a month while applying for Medicaid assistance. Larry easily qualified because the family lacked any savings or assets other than their house. The first Missouri-based facility she chose did not provide good care and Larry developed bedsores within a week. Joan transferred him to the nursing home where he now resides in Kansas.

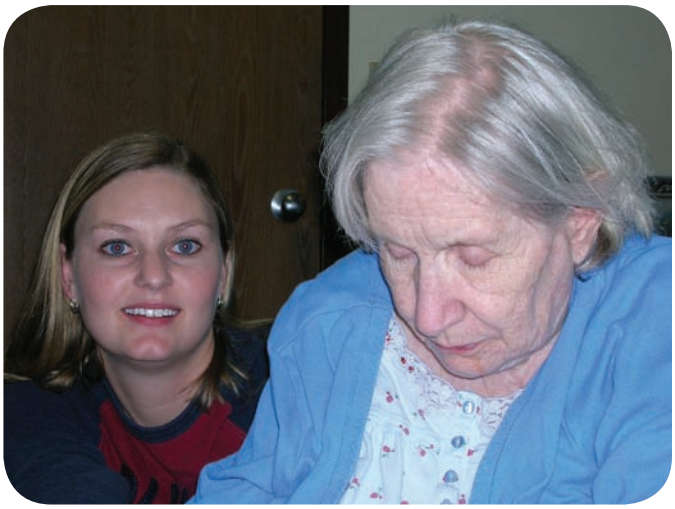
The long distances between Joan's home, the nursing home and her work create an extra burden for Joan. She considered moving Larry to a nursing home just minutes from her home, but the facility did not have the secure unit that Larry's care requires. Joan was also planning to sell her house to reduce her commute time but decided against this plan when she discovered that under Medicaid rules she would need to immediately apply the sale proceeds to the purchase of another home.

Joan on the value of having someone to talk to about eligibility:

They kept telling me you're going to have to sign up for health but nobody told me where to go or what to do…When I read about the eligibility rules in the book it didn't make sense, but when I sat down with Helen [from the state social services office] it made sense… Now they have taken that office out of here so I have to do it all through the mail. The nearest one is in Atchison. I miss that lady because she was the most helpful thing; it was wonderful because it was all frightening and it was at a bad time when you are really messed up.

Family Profile: **Pearl is 84. Her granddaughters Melanie and Jocelyn cared for her before she entered the nursing home.**

Location: **Rural Kansas**



When **Pearl**, 84, first showed signs of dementia her granddaughters Melanie and Jocelyn moved her from the farm where she lived to an apartment in a nearby town. Pearl did very well on her own for about a year before she began to deteriorate. Melanie and Jocelyn moved her into their own home and tried to take care of her there but quickly found they could not meet her needs for round-the-clock care. In 1998, after three months with her granddaughters, Pearl moved into a nursing home.

Pearl immediately qualified for Medicaid because she had no income or assets other than social security and a house and small farm purchased in 1952 with her husband, who died in 1987. The house and farm are not counted towards asset limits when qualifying for Medicaid. Pearl lost her eligibility for Medicaid, however, when she sold the farm in 2001 to Melanie and her husband. Proceeds from the sale made Pearl ineligible for Medicaid and were used to pay for Pearl's long-term care costs of about $3,200 per month. After these funds were exhausted in early 2004, Pearl re-qualified for Medicaid.

Melanie received very little help in the Medicaid enrollment process. While she did not find the process particularly difficult, it was long and required assembling her grandmother's scattered financial records. Although there are few nursing homes to choose from in the rural county where Pearl lives, her granddaughters wanted her to receive the best care possible. They were not happy with the care she was receiving at the first home she lived in, so moved Pearl to where she currently lives. The new location puts her closer to family and just a few miles from the farm where she spent most of her adult life.

Melanie on the choice of nursing facilities:

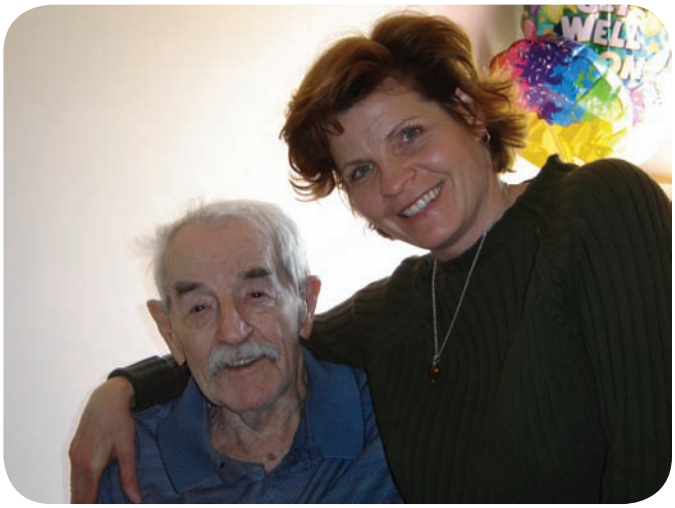
In a small community I wanted her close enough—there's not a lot to choose from in this county – but I wanted her close enough so that I could visit her and that she wasn't too far away.

Melanie on the application process:

It would be helpful when you pick up the application kind of like directions as to when this should be done, time frame, didn't know how much to wait. A little booklet to tell you how the process will work.

Family Profile: **Robert, 87, and his wife Marian, 85, share a nursing home room at a facility close to where their daughter Alice lives.**

Location: **Charlottesville, Virginia**



For almost ten years Alice worked to keep her parents **Robert** (87) and **Marian** (85) at home after her father's debilitating stroke and the onset of her mother's dementia. Until the stroke, Marian managed a homeowners' association and Robert was a contractor with a passion for stonework; he was laying stone for a patio the morning of his stroke. Within a year of Robert's stroke, and probably spurred in part by the heavy demands of caretaking, Marian's health deteriorated and she began showing signs of dementia. When it was evident the couple could no longer live on their own, their daughter Alice took them into her home. It was difficult for Alice to juggle a full-time job, single-parenting and care for her parents. She used available family and medical leave and took additional unpaid time off until she couldn't take any more. At this point Robert and Marian moved into their son's home, where they stayed for a year or two before transitioning into an assisted living facility near Alice.

The sale of their home and a small inheritance gave Robert and Marian a nest egg of about one hundred thousand dollars. Some of this money was used to pay for in-home care—at $15/hour—and to build a living space for them at their son's house. They spent the remainder, about $40,000, to pay for assisted living. The county-run facility, which charged about $6,000 a month, was the only one they could afford. Other private facilities charged twice this amount.

After six months the couple's money was running out. With no way to pay for assisted living, mounting medical bills and Marian's increasing need for care, Alice looked into nursing home options, frustrated that the only way the couple could get assistance from Medicaid was if they moved into such a facility. They moved into a nursing home in 2004, where they now share a room.

While they easily qualified for Medicaid coverage, it was difficult for the family to figure out critical steps in the eligibility process. This came as a surprise to Alice, who had a long career in health care and medical billing. The family consulted an elder care attorney for help, but could not afford his fees. Because Alice did not understand the process the couple was not able to retain the $2,000 in assets allowed under Medicaid.

On long-term care insurance: *They (my parents) had no money to pay for long-term care insurance. To me, [long term care insurance] is a benefit for the wealthy. The only people who can afford long-term care insurance are people who are well off in the first place.*

On wanting to stay at home: *Neither one of them wanted to be in a facility…[Just before they moved into the nursing home] they had no resources otherwise we would have tried to bring someone into the home and let them stay [there].*

Family Profile: **Roy is 78 and never married. His niece Lucy helped him find a nursing home.**

Location: **Charlottesville, VA**

Roy, 78, is a Korean War veteran who retired after 20 years serving in the army. Now suffering from Crohn's disease, diabetes, and dementia, he is in his third nursing home facility since 2001. Roy never married and lived alone for years. In the late 1990s his relatives began to notice his health was deteriorating. Roy's house, always a mess, had become chaotic. Roy wasn't paying the bills and was forgetting to take his medications. The responsibility of taking care of Roy fell to his niece Lucy. At first Lucy considered arranging in-home care for Roy and found someone who could come in 10 hours a day for $1,300 a month. But the poor condition of the house, the high cost of the care, and their concern about leaving him alone for any period of time, did not make in-home care a viable option. Assisted living was not an alternative because of Roy's inability to walk.

Roy entered a nursing home for a short period in 2001, then returned in 2003 as his health deteriorated. Unhappy with the care Roy was receiving, the family transferred him to a skilled nursing facility that had an Alzheimer's unit, where he stayed for a year. Receiving inadequate care for chronic pressure sores, Roy transferred to his current facility after another year.

Roy paid out-of-pocket for his first nursing home stays, selling his truck and some shares of stock, and using his army pension. When his money was about to run out, Lucy applied for Medicaid assistance in 2004. Unaware of the restrictions on asset transfer, Roy had transferred ownership of his house to Lucy and her brother in September 2003. Medicaid denied the application on the grounds that the house transfer had occurred within the 3-year look-back period. Realizing her mistake, Lucy sought legal advice on the enrollment process, then sold the house for $55,000 and reached an agreement with Medicaid to use the proceeds to pay off her uncle's unpaid nursing home bills and lawyer's fees and spend down until Roy was eligible. When Lucy reapplied for Roy's Medicaid eligibility a year later, the family also had to spend down before qualifying. During the previous year, the VA had awarded Roy a small lump sum payment, which Lucy used to buy Roy clothing, a new TV, and a chest of drawers among other things to bring him down to the $2000 asset maximum. He now gets $1,300 a month from the VA, of which all but a small amount goes towards reimbursing the state for Roy's care.

Although her uncle never considered—or likely was even aware of—long-term care insurance, the whole experience has made Lucy a believer. She now pays a subsidized $20 per month for long-term insurance care through her employer.

On in-home care: *People want to stay at home, they know their environment, if they are mentally capable of being at home that's different.*

Family Profile: **Natalie is 78. Last year she moved to a nursing home nearby her daughter Ellen.**

Location: **Charlottesville, VA**

Natalie, 78, entered the nursing home in June 2005. She and her husband, who died five years ago, raised their son Michael and daughter Ellen in a small town in southwestern Virginia. Her husband barely made a living working at a furniture factory, and the family never could afford a car when the kids were growing up. In 2001, her recently divorced son moved back home and shortly thereafter Natalie started showing early signs of Alzheimer's disease.

At first, Michael took care of her basic needs, but with a job and his own personal problems it became too much, and the family hired a friend to come in between 9:30 and 1:30 each day to bathe and feed Natalie, and to keep her company. Ellen helped out as often as possible, but was living 120 miles away. That arrangement worked fine until Natalie started to wander away from the house and it became clear they could not leave her alone.

Realizing her mother needed a higher level of care, and wanting to keep her at home if possible, Ellen talked to a county social worker about having someone come to stay with her mom. But for the county to pay for such an arrangement, they required that someone be with Natalie when the home aide arrived and left for the day. Michael's work schedule made this impossible, and so Ellen began to investigate nursing home options.

Ellen knew her mother would likely qualify for Medicaid assistance because she had few assets. Natalie's husband had transferred ownership of their home to the children 15 years earlier, after seeing a friend lose his home by having to sign it over to a nursing home. Natalie did not work outside the home after marrying, and her only income is $830 from her husband's monthly social security check. Ellen got the Medicaid application from the nursing home admissions office and filled it out easily, although she worries that elderly people might find the application difficult to navigate without help. Her mother qualified for Medicaid assistance after about one month.

On in-home care:

We wanted to have someone coming to stay with her, because you hate to take them out of the home. You know nobody wants to go to a nursing home.

On growing up poor and not knowing how to apply for public assistance:

If mom and dad had known how to apply for stuff, we would have been eligible for stuff; we were just really poor. We lived close to town and if we needed to get to town we walked. My dad walked to work every day.

Additional copies of this report (#7510) are available on the Kaiser Family Foundation's website at www.kff.org.

The Henry J. Kaiser Family Foundation: 2400 Sand Hill Road, Menlo Park, CA 94025
Phone: 650.854.9400 Fax: 650.854.4800

Washington Office: 1330 G Street N.W., Washington, DC 20005
Phone: 202.347.5270 Fax: 202.347.5274

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Medicaid and the Uninsured